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How To Solve A Problem Like ME/CFS: Why The Gibson Report Has Failed Patients.

By Lara

Tackling the inaccuracies in the Gibson Report must be the task of the century. Having read it I have struggled to think of a succinct way to sum up its enormous failings. Some of it was just plain nonsensical (we don't know the cause, but we know it isn't Lyme borreliosis), some of it farcical (Simon 'poor me' Wessely wouldn't come to the 'inquiry' because some nasty patient groups ganged up on him) and some of it dangerously inaccurate (the Munchausen by Proxy reference). However there is one overriding problem within the report in my opinion, which I believe stands out against all the others. The following extracted from the report demonstrates the issue:

*"This association with infections has prompted a search for infective agents and there is now reasonably convincing evidence **that some infections do precipitate the illness.**"*

*"Research has focussed on each of these possibilities **but a search for continuing active infections has been uniformly negative** even though tests of past infections remain positive as they do in those who recover fully."*

*"Future research therefore needs to focus on efforts to categorise the illness or illnesses and on **possible infective or other precipitating causes** and into the factors contributing to a person's predisposition to the disease."*

*"There is a need to undertake **further research of post viral infective cause** in carefully controlled studies."*

*"The Epstein Barr virus was thought to be principally responsible for CFS/ME for some time, the more recent virus to enter the debate is the Coxsackie. This is because they have an immunosuppressive effect which potentially causes the symptoms of CFS/ME. Viruses are areas which need further research. It is clear that fatigue is a much recorded post-viral symptom. However, **there is not enough evidence to determine whether post-viral CFS/ME is a separate illness from CFS/ME.**"*

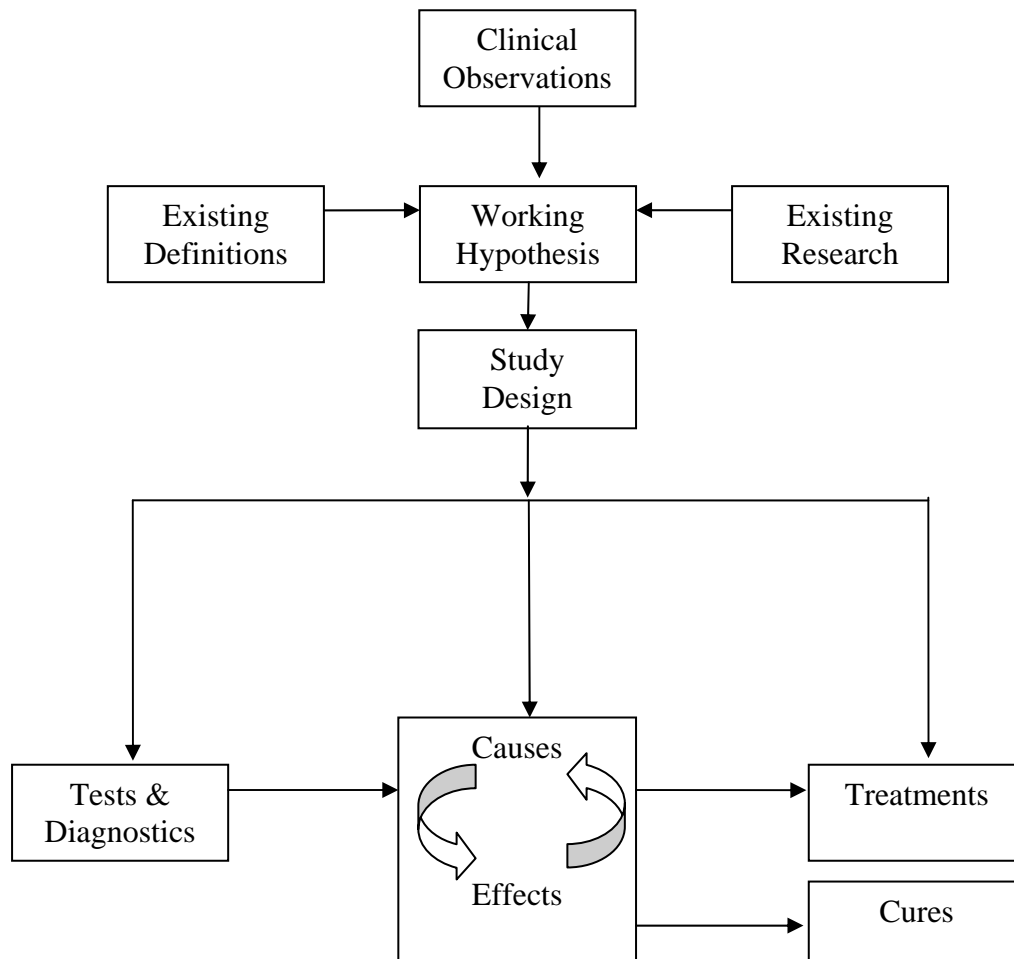
With the casual wave of the hand and not a sniff of a reference, the entire evidence-base of current and on-going infections in ME/CFS was discarded.

The Canadian Guidelines (CG) for ME/CFS [1] (which ironically, appeared in the Gibson report) contains at least 30 references in the original document (judging from the title alone) looking specifically at on-going infections in ME/CFS patients (e.g. HHV-6, HHV-7, mycoplasma, chlamydia etc) and there are many others which did not appear in the CG. All of these seem to have been ignored by the Gibson Inquiry. What emerged instead was a dogged adherence to the concept of 'post-infectious fatigue'. In truth this premise bears little difference to the psychiatric paradigm and simply suggests patients have some unique inability to recover from a viral infection or 'other precipitating cause'. This model is however placed under the 'biomedical' banner in an attempt to win patient support.

Adoption of such a tactic is likely to delay appropriate tests and treatments for ME/CFS patients for the best part of a decade or more and to waste large sums of taxpayer's money. In the meantime the psychosocial lobby will be able to steamroll ahead unchallenged by government with its un-evidenced and harmful CBT/GET approaches financed by a huge cash handout in the form of £180 m of UK taxpayers' money.

In contrast to the Gibson report, I would like to back up my statements with a little logic and a few key references. It may be helpful to consider an approach based on the schematic below.

Schematic Approach to Treating ME/CFS Labelled Patients



So how do you solve a problem like ME/CFS? Well, perhaps, we could look at ALL the research published to date and consider the existing findings as potentially worthy of larger scale clinical studies (you know like those ones the psychiatrists get all the money for). Yes and you might also want to consider the clinical observations made by doctors who have treated innumerable patients labelled with ME/CFS, the sort of thing that they present at conferences, even if they can't always obtain funding for larger trials or get the results past the psychiatrically biased peer review process. Oh and you might want to consider the definitions of the disease as set out, especially the most up to date ones, which were based on the hundreds of "authentic" biomedical studies and clinical experience to date. So what do you do next?

- a) Ignore 90% of the information and plough ahead unabated with highly controversial and harmful psychosocial approaches?
- b) Set up a committee, have lots of tea and biscuits and come up with some sort of half-baked compromise that attempts to make the psychiatric lobby look less like the charlatans that they really are?
- c) Hone in on the key issues such as large scale testing for infectious agents, postulated time and again to be causative in ME/CFS labelled patients? Check out markers that seem to be positive in large numbers of patients such as abnormal RNASEI pathways, lymphocyte counts? Check out nutritional deficiencies such as Vitamin D ratios, low zinc, low magnesium, blocked ATP pathways?

OK, forgive the satire, there really is no need for answers on a postcard. So, now having chosen a real 'biomedical' Working Hypothesis, and some decent areas already researched to date, what do we do next?

- a) Give all the money to anyone with BA(Psych) or preferably FRCPsych after their names (he's a paediatrician honest, love) and watch them laughing all the way to the bank?
- b) Get your psychiatrically-biased, sold out buddies of doctors and researchers to round up some Fukuda patients (you know, the ones who seem a bit tired, fed up of work, menopause not far off, husband's run off with the babysitter). Send them in for the studies, which will of course be negative or at best inconclusive?
- c) Choose patients who best fit the clinical definitions based on "authentic" biomedical research and send them off to have some serious scientific investigations?

Well, again, this isn't a GCSE examination, more like a PhD in the blindingly obvious. So now we're warming up how does all this research fit together? What are we going to use as a test? How are we going to know what is a cause and what is an effect? Do we ever know that in a disease, or do we just find out what is treatable and proceed with clinical treatments?

Well, I guess we'll just have to be flexible, because if we spend all our time just looking for a single cause, test and treatment, we might not get anywhere for years and years and that would never suit, well....anyone except psychiatrists and psychologists really, as they seem to get paid by default until we can find out the 'cause' of this otherwise 'medically unexplained condition'.

Perhaps in choosing a more homogeneous set of patients (based on the CG criteria) and choosing a raft of tests that have been studied in the past, then eventually through an iterative process using something a bit like the schematic, one might obtain a better way of diagnosing and treating patients. If infections are found early on as a cause, these can potentially be treated, but in addition effects could also be used as diagnostics, or as individual areas for treatment.

Without wishing to limit the approach, the emerging evidence that Tick Borne Diseases (TBD) have been misdiagnosed in many cases as ME/CFS must be addressed as a priority. A comparison of the CG symptoms with the ILADS guidelines (IG) for Lyme Disease (encompassing lyme borreliosis and other TBD) reveals a stark similarity. In fact I can barely find a symptom that does not have

a match. Unsurprisingly this was the conclusion of the authors of the IG who stated:

“The clinical features of chronic Lyme disease can be indistinguishable from fibromyalgia and chronic fatigue syndrome. These illnesses must be closely scrutinized for the possibility of etiological B. burgdorferi infection.”

Comparison of ME/CFS Symptoms with Lyme Borreliosis

ME/CFS (CG)	Lyme Borreliosis (IG)
Physical and mental fatigue, post exertional fatigue/pain	Fatigue
Unrefreshing Sleep	Sleep Disturbance
Pain (muscles, joints, migratory, shooting, burning, aching), 75% meet criteria for Fibromyalgia Syndrome (FMS) Temporomandibular Jaw (TMJ) dysfunction	Myalgia, Back Pain, Jaw Pain, testicular/pelvic pain, stiff neck. Migrating arthralgias, stiffness and, less commonly, frank arthritis,
Headaches	Headaches
Muscle Weakness and Fasciculation	Muscle twitching
Intracranial abnormalities	Cranial nerve disturbance (facial numbness, pain, tingling, palsy or optic neuritis)
Low Body Temp, Sweats, chills, cold extremities, intolerance to hot/cold	Low grade fevers, hot flashes or chills, night sweats,
Sore Throat/Flu symptoms/ Tender Lymph Nodes	Sore Throat/ Swollen Glands
Orthostatic Intolerance (NMH/POTS), palpitations, cardiac arrhythmias, dizziness, vertigo, extreme pallor	Chest pain and palpitations, light-headedness, dizziness, vertigo, cardiac symptoms
Visual impairments	Blurred Vision & Eye Pain
Memory Impairment, Difficulty with information processing	Poor Concentration and Memory Loss, Cognitive dysfunction
Sensitivity to Light & Noise	Tinnitus, photosensitivity
Emotional overload/anxiety	Irritability and mood swings, depression
Marked weight change, anorexia, loss of appetite	Abdominal pain/nausea
Multiple Chemical Sensitivity (MCS)	*
Sensory/Perceptual Disturbance	Paresthesia**
Urinary Frequency & Bladder Dysfunction, IBS	Diarrhoea, urinary frequency**

* While MCS is not specifically mentioned in the IG, other researchers have noted it as present in Lyme Borreliosis patients [3]

** These symptoms were not specifically mentioned in the IG, but again have been noted by other researchers [4]

Looking at the comparison of ME/CFS it is almost impossible to see how mixing up the ‘two diseases’ could be avoided. Certainly a General Practitioner, who has been advised that in the case of ME/CFS only routine tests are necessary, it is highly unlikely that he/she will be able to tell if they have correctly diagnosed the patient. This comparison of the CG and IG alone highlights the extreme need for ME/CFS patients to undergo thorough testing for TBD pathogens. In avoiding the issue, the Gibson report may have entirely missed the point and the opportunity

to progress ME/CFS research and treatments in a manner helpful to many patients sitting under this label. It is a great pity that the Inquiry did not look deeper into this issue and that it did not invite a range of experts with experience of diagnosing and treating TBD to give evidence. Limiting themselves to taking advice from the UK Health Protection Agency (HPA) and subsequently deciding (in the absence of the knowledge on what causes ME/CFS) that they must be two separate diseases, constitutes an incredibly blinkered and closed-minded approach that is no different from the manner in which the psychiatric lobby operates.

One can now only hope that the Gibson report has not done more harm than good and that future research will include testing for bacterial and viral infections in ME/CFS patients, a good part of which could be achieved using the £180 million earmarked for CBT/GET therapies. One thing is certain, in any judicial review going forward a vigorous campaign for testing of infectious diseases must be kept up. Patients simply do not have another decade of their lives to give up to tail-chasing, closed-minded and flawed research and treatment approaches in ME/CFS.

References

1. Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols. Journal of Chronic Fatigue Syndrome Vol 11, 1, 2003, Carruthers et al.
http://www.theoneclickgroup.co.uk/documents/ME-CFS_docs/Canadian%20Definition%20of%20ME-CFS.pdf
2. Evidenced-Based Guidelines for the Management of Lyme Disease, The ILADS Working Group, 2006.
http://www.ilads.org/files/ILADS_Guidelines.pdf
3. Lyme disease: ancient engine of an unrecognised borreliosis pandemic? Harvey W.T and Salvato P. Medical Hypotheses 60, 5, 742–759, 2003.
www.ilads.org/files/harvey.pdf
4. Issues in the Diagnosis of Lyme Disease. Donta S. Lyme Disease Action UK 6th UK Tick Borne Conference, Sheffield, June 2006
<http://www.lymediseaseaction.org.uk/conf2006/donta/img0.html>